**Disability Advocacy Research in Europe (DARE)**

**‘Change & Disability**

***The Researcher as Policy Entrepreneur.’***

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# Introduction

It is a pleasure to be among the next generation of young researchers and hopefully aspiring change agents.

I am deeply grateful to Lisa Waddington for the invitation. I readily accepted in part because of my admiration for her own sterling contribution to change.

In her inaugural address she wrote eloquently about the march of an idea from the Treaty of Rome to the Treaty of Maastricht – in a wheelchair. The journey she traversed in that inaugural address was from meagre origins in the Treaty of Rome to much more promising normative departure points in the Treaty of Maastricht.

What I want to do today is bring you on a different kind of journey.

My chief concern today is what counts as change? Why is change so difficult even when the evidence is overwhelming and the normative departure points crystal clear?

To do that I want to unpack two spheres that may considered markets in their own right and then to focus on the relationship between research and these markets. Of course, they are more than markets – but let me stay with that metaphor for the sake of this talk.

First of all, there is the political marketplace which responds, in its own peculiar way, to the felt needs of the people. There are many prisms though which issues get refracted, ignored or made salient in this marketplace. There are many dynamics explaining change – or lack of change in this marketplace. You need to know how this marketplace works and your place within it.

Secondly there is the policy marketplace or permanent Government which can be equally, if not more, resistant to change. We can condemn – but it is better to understand. Often the political market place and the policy marketplace are not aligned. But when they are great things can happen.

Spoiler alert – I am assuming a relatively open and responsive democratic order. That of course is not true everywhere in the world. You will have to adjust what I say to fit with your own circumstances in whatever part of the world you come from.

Not only can the political and policy markets take a different shape depending on where you are but culture often mediates universal norms. Still, I am optimist and I believe that openings for change do occur even in relatively closed political systems – you just have to be alert for them and ready to capitalise on them when they occur.

Third, what about your *forte* – research, knowledge, data and evidence? What is its relationship to change – to these two marketplaces - and to advocacy within and before them?

The relationship between research, ideas and change turns out to be very complicated.

Disabuse yourselves of the idea at the outset that there are any self-executing treaties, directives or other legal norms. Always remember the admonition of Justice Holmes that “the life of the law is not logic, it is experience.” Formal logic may point one way – but it is often mediated by other factors that courts, politicians and policy-makers, for example, simply assume.

It is much harder to excavate these assumptions – and then create a space for decision-makers to feel comfortable abandoning them. One of the key lessons of the Legal Realists is that decision-makers do not necessarily respond to cogent argumentation. You have to first make them want to decide for you. A cursory reading of Jerome Frank’s ‘Law & the Modern Mind’ makes this abundantly plain.

I think it is useful to travel this field before you begin your life’s work and journey. Academic prowess is one thing. But the ‘situation sense’ needed to move the dial forward is something else entirely. As you gain experience you will pick this up – hopefully. But is no harm to be aware of this before you begin your exciting life journey.

# The political Market Place and Change

What about the political marketplace? What moves politicians? I want to zoom into a few elements. I am sure there are more.

As a true marketplace, political parties and individual politicians compete for votes and power. Our hope is that this creates a discipline to think about the *public interest* rather than sectoral interests. But of course we know that some parties favour some sectoral interests over other parties. That’s part and parcel of their very identity and appeal to the public – or at least to sectors of the public.

Very few politicians are conviction politicians. Almost like political algorithms, they can sense trends and adjust accordingly. Likewise, very few political parties reason deductively from core instruments like a Constitution or a Treaty. They constantly weave and respond to where they sense the public is going. One of our former Prime Minsters was an exception – he famously said ‘this is all very well in practice but will it work out in theory?” Most politicians do not think this way.

So how to hail them on their channel?

The first element I want to focus on is on values.

**Values:** All political systems have their own traditions and ground norms – legacy values. A good example is the centrality of equality in the French Republic. Another might be the desideratum for fairness in the UK.

No party wants to be outmanoeuvred when it comes to these core legacy values. It helps to be able to point to a treaty of a Constitutional provision. But to reinforce native commitment to change you need to also point to these legacy values.

Of course all systems have a degree of cognitive dissonance – professing one thing and then doing the other – with absolutely no sense of contradiction. I have often puzzled about this.

The only explanation I can find is that culture often trumps logic – even the logic of a legacy value.

This gets back to the importance of narrative in framing the issues and the critical importance of configuring your research and policy interventions to crack open that narrative.

Parenthetically, that’s why I think Article 8 in the UN CRPD (nurturing receptiveness to rights) is so important and underappreciated.

**Economics:** Another way to reach politicians is though economic argumentation. I believe it was James Carville who once said ‘it’s the economy stupid’ as a way of explaining voter’s behaviour - and politicians’ behaviour in response.

Politicians know instinctively that people will not vote for them if they feel worse off than before. Now that’s useful – up to a point. Never forget that the constitutional authority for the ADA was both the 14th amendment (with its moral allure of equality) with the inter-state commerce clause – working toward a more rational and efficient trans-border national economy. Likewise, never forget that the logic of the internal market also sits alongside Article 13 of the Treaty of Amsterdam as providing authority for key EU legislative developments.

Curiously, the economic argument does not always work in your favour *even when it should*. For example, institutions are widespread in many countries. They are expensive and are palpably inefficient in terms of human outcomes. And yet they persist. Another example, DG REGIO continues to invest the hard earned monies of ordinary European taxpayers in institutions even though the great Jim Mansell showed there were better solutions many years ago.

Whats’ going on? You’re a politician right? You don’t want to be seen throwing people out of a job. And the the cost of the existing situation can be borne out of fear that change will rupture the economic interests of an important group that actually vote. Others have suggested that corruption plays a part although that is intrinsically difficult to establish.

But maybe what is really going on underneath the surface is that economic arguments (no matter how well crafted) are always seen through a distorting prism. Its’ like economic arguments have traction sometimes but not always Quite where the dividing line is, is hard to predict. Reputedly, the John Major Government sat on (i.e., did not publish) research that showed that making the preponderance of London underground stations accessible would pay for itself over a number of years.

So economics counts but it is not a killer argument for change. Still, be prepared to make the economic argument. Sam Bagenstos claims this was the argument that cemented the bi-partisan support for the ADA.

And be prepared for the reverse. The economics may not point to the solution you prefer – but have the strength of character to press for it regardless of economics. At the end of the day, human rights trumps economics – but politicians rarely see this.

**Scandals and moments of Crisis?:** What about the unique opportunities opened up by scandals – of which there are many in the disability field? Politicians have an acute sense of how the public reacts to events especially to scandals and tragedies. These moments of crisis and self-doubt often create a temporary space for change. If you don’t move fast you will lose the momentum. You have to be prepared – and have your own blueprint for change ready before a crisis hits.

Of course, it can backfire spectacularly. I remember an episode here in Ireland whereby our national TV did an expose of violent and inhumane conditions in an institution in a neighbouring county. I did an appearance on national TV on it. I came out of the studio and had an informal chat with the camera man. His reaction was the common reaction – we can surely do better regulating conditions in these places! It was not, ‘hey we actually have a national policy on deinstitutionalisation that is not being implemented and no matter how well regulated these places are they are intrinsically prone to violence, exploitation and abuse.’

I was shocked. But I shouldn’t have been. The space opened by scandal and the human reaction of pity can also be dominated by pity. The trick is to try and use the space opened by scandal and shock as well as pity to engineer space for real change. The scandal and ensuing pity can exceptionally create the space – *but should never be allowed to drive it*. Thats much easier said than done. You have to somehow use the moment of crisis to engineer a shift of narrative - but more of that later.

**Accidents:** Never underestimate sheer accidents and be ready for them.

A case in point. When Theresia Degener and I produced the UN OHCHR Study in 2001 on the need for a treaty it was against the backdrop of a failed resolution in the Human Rights Commission to move toward a treaty. Rather, a draft resolution to that effect was vetoed even before it got to the floor by two or three European States (which I won’t name here). Those States said it was too early – that the existing system should be given more time to work. The aim of our Study was to show that the existing system did not work and could benefit from a new instrument. In truth, any new resolution based on the Study was also likely to fail since the opposition was deeply entrenched. Nobody – especially not us – could have predicted that Mexico would short circuit further debate by pushing through a resolution in the UN GA to set up an *Ad Hoc Committee*. The rest is history. My point. Accidents do happen – they create space for innovation. Don’t hold back on your ideas for change. What is unthinkable today can suddenly become the norm tomorrow.

**Playing the Competition game in the Marketplace:** All marketplaces have competitors. Often, rival parties will focus on an issue like disability to both embarrass the governing party and burnish their own reputations. Equally, the governing party might move on an issue to deny oxygen to a rival party. The best is all-party support for change – but doesn’t happen often. The ADA is a great example.

Competitive political dynamics may work in your favour. However, a lot of care is needed.

If you get too close to a rival party (thus enabling them to attack the Government and make political capital) then you may find ourself locked out of favour with the governing party. Say, you craft a blueprint for new legislation and it is championed by an opposition party. Merely the fact that is championed by an opposition party may doom it – despite its intrinsic merits. And if the governing party looks set to lock in place its majority then you will be left out in the cold. Contrariwise, if you get too close to the governing party then you can easily be portrayed and criticised for appeasing inaction.

It’s a very delicate game. My only advice is don’t unnecessarily burn bridges, make yourself equally available to all parties. Try not to be seen as weaponizing one party over another.

**Interest Group Articulation and the reduced impact of ‘Discrete and Insular Minorities’:** Of course every market has both a supply side and a demand side. On the demand side the other interesting thing about the political marketplace is what the political sociologists call interest group articulation and interest group formation and agitation. Politicians and political parties don’t respond to individuals on the ground. More accurately, they don’t typically formulate policy on the basis of individual experiences. These experiences are mediated through interest groups like OPDs who garner attention. And these interest groups also compete with each other.

The theory about ‘insular and discrete minorities’ posits severe disadvantages for many social groups who find it hard to form alliances with other groups and thus leverage change. Some disability groups have been disadvantaged by this – and sometimes even fail to get the active support of other disability groups. Sometimes governments will play to the distinct interests of different groups and play them off against each other. And sometimes governments will frame the arguments from interest groups like disability rights groups as just special pleading – an attempt to hijack rights to advance special interests.

This speaks to the need to build alliances – which takes a lot of mental energy and time. To me at least, it also speaks to the need to work much more intersectionally. I have often marvelled at how elder rights groups are still at a distance from disability rights groups. When you think about it, deinstitutionalization affects both. And this might lead to more sustainable policy solutions across identity boundaries. Probably the future is increasingly intersectional. I only see that as a gain.

The important point is to reflect on the eco-system for the demand side – how to anticipate how your positions might be spun by Government and to have a counter-narrative, how to form alliances within the disability field but also beyond it, how to overcome prejudice against ‘discrete and insular minorities’ to ensure your voice is heard commensurate with your numbers and the importance of issues raised. In short, tend to the eco-system on the demand side.

# The Policy Marketplace and Change

So much for high politics. What about the ‘real government’ – the permanent civil service who often function as the key gatekeepers of policy change?

Research conducted by the British overseas aid office a few years ago investigated why, after a significant investment of several hundred million pounds to a donor country, there had been little lasting impact. The surprising conclusion was that the policy narrative of the key policy makers had not changed. The result was that money was funnelled into the system without, in any meaningful way, re-shaping the old policy narrative. They also came to the startling conclusion that senior policy makers tend to truly innovate only once over a long career – twice if you are lucky! They are risk averse.

Now, what we typically call for in the disability sphere is innovation which means taking risks. When you think about it, the CRPD is a disrupter. The systems changes it envisages run deep and wide. That’s why *we* celebrate the CRPD.

To me the important finding concerns the centrality of narrative. Two things seem to me to dominate the controlling narrative almost everywhere in the world.

**Be Thankful for Social Support:** First of all, there is the assumption that social support in the form of traditional social welfare is not only enough but you should be thankful for it. When you unpack this you can see how it subtly objectifies the person and accepts that a floor of material support is not only necessary but also sufficient. Related to this in the dominant policy narrative which is that ‘disability costs.’ So there is a tendency not even to reach the merits of the arguments for change. The cost paradigm operates as a curtain to pull across arguments for change and put them on the defensive. And this is true even when the arguments for change are palpably cost-effective.

I recall the initial opposition of the EU to the concept of ‘reasonable accommodation’ in the Ad Hoc Committee in the drafting of the UN CRPD. They saw it as an indirect way of making economic and social rights enforceable – and therefore objectionable. The initial position was impervious to logic. Thankfully, they changed – but that’s’ another day’s story.

In a way, persons with disabilities are caught in a trap of economic, social and cultural rights. Rather, these rights are often distorted to justify arrangements that may provide support but at the cost of marginalising persons with disabilities. It seems that disability (and old age) are disproportionately hit by this phenomenon – welfare and not rights. When you argue for enhances social support be careful not to reinforce the dominance of the welfare model.

**The Centrality of Policy Narratives:** Related to the centrality and stubborn stability of dominant policy narratives is risk. The risks associated with existing law and policy are known-knowns. Often, policy makers are actually content to continue with these risks even though they exposure persons to human rights abuses. For example, to be placed in a congregated setting means a heightened risk of violence, exploitation and abuse. Part of the reason for keeping people in institutions is protection. Yet is had been shown time and again that the best form of protection is to have a friend.

The risk of continuing with existing arrangements is balanced in the policy-makers mind with the risks of change. Change is inherently risky. It is an unknown-unknown. The costs are unpredictable. The rupture to existing ways of doing things will discomfort many. Why create enemies. It creates the risk of a spill-over - other groups might be emboldened to demand change. Policy makers might lose control of the agenda. You and I celebrate this – but policy makers don’t.

**Changing the Policy Narrative – a Long Game**: So if the policy narrative is key then how can we change it?

You stand some chance to persuading the policy gate keeper to innovate if he or she has political cover from the political branches. This assumes a minister committed to change. This commitment might either come from conviction or from political calculation. But if it is there then the innovation-minded policy maker can use it to advantage. There will be mistakes – but at least there will be political cover.

And you stand some chance of success if you can show that the new framework – though unfamiliar – promises better outcomes as well as a more rational use of public resources (the field that counts permanently).

I digress for a moment. It seems that dominant policy narratives have their own half-life. That’s is to say, they decay slower than the pace of legislative change. An obvious case in point were the many negative policy reactions during COVID-19 – as revealed by the outstanding Disability Rights Monitor report in 2021. So even when there is positive legislative developments the dominant narrative continued and explains the many negative policies that impacted persons with disabilities during COVID notwithstanding legislation to the contrary. Systems always revert to type.

Lisa Waddington is best placed to assess the impact or the overhang of these stubborn policy narratives in the courts. But I think it is a fair guess that they impact the interpretive posture of the courts even to modern legislation.

So changing the dominant policy narrative is not necessarily done by enacting positive legislation. That’s’ only one step and not necessarily the decisive one. Changing the policy narrative is a long game. It means that you have to consciously configure your research and advocacy interventions to chip away at the dominant framework and to put in place an alternative framework – one that can stand the stress of crisis.

# Ideas, Research & Change

Ah, now we come to you – the knowledge workers of the future.

By now you will understand that change is complex – there are many moving parts and it does not necessary respond to rational argumentation – or at least not directly. I think there are important lessons for how you should approach your future as knowledge workers.

**Avoid the Naturalistic Fallacy:** In the past, a lot of disability research focused on explicating reality and typically though quantitative analysis. Nothing intrinsically wrong with that. However, the dominant policy narrative has a way of distorting the messages to be derived from such research – even though this is not your intention. Detailed *exposes* of ‘what is’ can be easily distorted into an understanding of ‘what ought to be’ – the classic naturalistic fallacy.

If quantitative research is your *forte* or if you are using quantitative research to augment more policy-oriented work then think about how you can guard against the naturalistic fallacy and foreground you vision for the future.

There is a lot of talk these days about evidence-based policy making. In my experience the evidence can count most when decisions have already been made on other grounds to change. That’s not to say that evidence is irrelevant. You can’t do without it and if you don’t have it, this can be used as pretext to delay change.

**Consciously seek to change the Policy Narrative:** All research work rests on often unarticulated presumptions. Try to bubble them to the surface. Remember, that even famous legislative breakthroughs can be side-lined if the dominant policy narrative persists. Everything you do will either support or undermine the dominant policy narrative. Whether you like it or not, you are a participant in the half-life of these narratives.

Your advocacy strategy – how you put your research to work – should keep one eye on the gain you seek to make (an inclusive education law) and another eye on nudging the narrative. Remember, the legislation on its own will not necessarily do it. Don’t be afraid to lay down the basis for a completely new policy narrative. Remember crises and accidents do happen and create oxygen for a switch in narratives. Don’t just challenge exclusion and segregation – challenge the suppositions that make it acceptable in the eyes of some.

**Avoid Legal Formalism:** Three ‘sins’ of legal formalism were highlighted by the Legal Realists many years ago. The first was *conceptualism* – the idea that legal ideas are both comprehensive (extending to all eventualities). The second was the idea that rules are complete unto themselves (entirely self-referencing). And third was that formal logic alone could generate one right answer.

Their core point was that law opens a deliberative space and does not close it down. There are very few single right answers in law – in Constitutional law and under Treaties. There is mainly argumentative space – which is usually a decided advantage compared to what existed previously.

It is tempting to be a legal formalist – to assert there is one right answer especially when the existing situation is intolerable. However, to insist on this you can invertedly play into a trap. Politicians and especially policy-makers hate it when you press an argument that short-circuits the ‘normal’ democratic process (i.e. that trumps the political and policy marketplaces) and this is true regardless of the merits. And most treaties (not to mention constitutions) contain weasel words that create space for open-ended balancing tests. After all, most of the rights in the CRPD are said to be secured ‘on an equal basis with others’ – whatever that means.

So in a way, a treaty or a constitution creates a space for deliberative reason. It’s a space with a difference as it grounds a completely different policy narrative. But no treaty is ever self-executing.

Always be aware that the CRPD treaty is a profound disrupter and flows directly against the prevailing policy narrative. Your work is to flesh out that new policy narrative. Try to avoid advocacy that suggests there is one right answer or that a treaty provision dictates an outcome. Try instead to present your research as a contribution to building a new policy narrative on the assumption that your system has committed to change since it has ratified the relevant treaty. In this, I at least, I am a follower of Ryan Goodman who vies international law less as a series of categorical imperatives and more as a stimulus to motive and nudge States toward right behaviour.

**Listen to - work with civil society:** The future is not to do work ‘for’ but to do work ‘with’ civil society. Partly this goes to the very legitimacy of your research work. And partly it goes to the effectiveness of your research work.

When Bob Burgdorf wrote the first draft of the ADA in the mid-1980s (which he did in his spare time) he did it in close cooperation with disability groups. This was one of the main reasons it was endorsed by the US National Council on Disability in two famous reports in the late 1980s thus paving the way for the landmark legislation.

This places a premium on models of co-production with civil society – as well as on research ethics when research work is done with civil society. The days of the isolated researcher working away in an ivory tower are over. This calls for new skills and especially active listening.

This may generate some tensions for you. After all, this kind of work product – generated through co-production - is not really what universities typically reward. I had high hopes for the trend toward rewarding work for its ‘impact’ in universities – but ‘impact analysis’ in research at universities has become reified and has therefore just become just another matrix.

At the end of the day, you have to do this work because you believe in it and not because it leads to career advancement.

**Circulate, Circulate, Circulate:** By now you will understand you are part of a larger eco-system for change. By now you will understand that each side of the equation has its own calculus. By now you will understand that motivating all sides to move forward is key. To some extent that requires you to make calculations for each side before they make them for themselves. This is the key to the ‘situation sense’ needed to advance change.

The best way to do this – to pick up the skills needed to do this – is to step into the shoes of the different sides. The idea that there is one unilinear career – for example in academia - is not helpful. Be open to spending some time in Government. There is no magic line separating good guys from bad guys. Be open to spend time working in advocacy organisations. Active listening becomes a natural default when you do. Spend some time in an NHRI or on a treaty body. They will force you to translate majestic generalities into practical lines of reform.

The acuity of your research product is greatly enhanced by all these experiences – not diminished.

# Conclusions.

First of all, the dominant policy narrative is the superstructure to change – guiding it, deflecting it and informing it. You should always have one eye on it while advancing a particular law or policy reform issue. Remember, unless changed, the dominant policy narrative can swamp even progressive laws in times of crisis. This is a long game but one that you should always be part of.

Secondly, your opportunities to put ideas into action depends on many variables – and not just on the intrinsic worth of the ideas. Don’t’ wait – always anticipate openings for change and be ready for them when they happen. And as Lisa Waddington and I can testify, they happen in surprising ways.

Thirdly, avoid legal formalism. Try to present your ideas as a contribution to deliberative reason – as an honest attempt to advance changes in the policy narrative. Be open to the counter-argument that you could be wrong. Prowess has to be tempered by humility.

Finally, try to circulate in your future career. Universities are *a part* of the world as well as *apart from* the world. They are at their best when they allow for, and facilitate, active citizenship. See your career as part of the larger democratic ecosystem for change and find ways to be connected. Life is short. But if you do this you are much more likely to leave some lines in the sand.

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